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Original Article

Changes in Symptoms and Pain Intensity of Cancer Patients After Enrollment in Palliative Care at Home

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Abstract
This study describes the activities and interventions carried out by an at-home palliative care team treating cancer patients who died within two years of being enrolled in a palliative care program. It analyzes which changes in symptoms and pain occurred and which sociodemographic and medical characteristics were related to these changes. The analysis is based on 102 cancer patients. Data were collected through systematic registration during the palliative care process. At enrollment, patients were interviewed by the coordinating general practitioner concerning their sociodemographic background, medical history, psychological status, and symptoms. During the palliative care process, symptoms and functioning of the patients were recorded by the physician and nurses. The results show that cancer patients enrolled in palliative care at home have many symptoms, often associated with metastatic disease and comorbidities. The palliative care teams delivered frequent and various interventions. The number of symptoms decreased considerably, as did pain intensity and the intensity of other symptoms. Patients living in urban areas and with low income particularly benefited from a reduction in the number of symptoms they displayed. Cancer patients who needed palliative care benefited significantly from this at-home palliative care service. J Pain Symptom Manage 2007;34:488–496. © *2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words
Palliative care at home, evaluation of palliative care at home, advanced cancer, symptoms, intensity of pain

Introduction

Progress in medical technology and clinical treatment has had considerable consequences for primary health care. The number of chronically ill patients has risen continuously in the Western world during the last decade and will continue to rise.[1] Due to advanced treatment, formerly fatal diseases have become merely chronic.[2] Chronically ill patients are mostly treated by general practitioners and cared for by family members and home care organizations.[3] As a consequence, palliative care has also become part of primary health care, and primary care providers are having to deal more often with a variety of complex

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symptoms of terminally ill patients at home, as well as a wide variety of other patient needs.[4,5]

It is important to have information on how the disease and its symptoms evolve in the last months of life and what may be done in primary care to control symptoms and to improve the quality of life of the patients involved.[6–8] Although several researchers[7,9,10] show that most symptoms do not worsen after patients are enrolled in palliative care, this pattern may change during the last few weeks of life. Functional status has been reported to worsen during the last weeks of life.[9,10]

Developing and providing palliative care at home is increasing all over Europe, especially in Eastern Europe.[9] In Romania, the need for palliative care for oncological diseases, dementia, AIDS, and other chronic diseases is large, but this kind of service is scarce, especially at home.[10] Primary health care has an important role in supporting and developing these kinds of services, in line with the population's preference to be cared for and to die at home.[11] As a result of the traditions and the mentality of Romanian people, most patients die at home. Studies show that 90% of patients live their final year at home, whereas in Western Europe the figure is quite different. In the UK, 26% of patients with cancer died at home.[11] In the USA and Canada, the percentage of patients dying at home varies from 10% to 15%, whereas in Denmark and the UK the percentage is 24% and in Poland, 48%.[12]

It should be recognized that palliative care at home for terminal patients is not simple.[11] It is very important to know the variety of patients' needs and how those needs evolve in the last weeks of life to provide care and to guarantee quality of life for patients and their families.[7,13]

This study describes the evolution of cancer patients' symptoms in the last period before death and the palliative care provided at home during this period by multidisciplinary teams. This information may be helpful in identifying better methods of care and in evaluating the quality of care provided.[4]

The research questions are the following:

1. Which changes occur in symptoms and in pain among patients taken care of in an at-home palliative care program from enrollment till death?
2. What activities and interventions do the at-home palliative care team (general practitioner and nurse) undertake during that period?
3. Are sociodemographic factors, the activities and interventions of the palliative care team, and medical characteristics related to changes in symptoms and in the intensity of pain felt by the patient?

Methods

This study was carried out in two regions of Romania (Olt and Bucharest). A Dutch-Romanian project, it was carried out over 24 months (October 2002–September 2004), during which five multidisciplinary teams (general practitioners, oncologists, nurses, and social workers) provided palliative care at home to patients in rural and urban areas.[14] In that period, 119 oncology patients were enrolled in the at-home palliative care program. Of these patients, 102 died during the assessment period and are the focus of the present analysis.

For every patient, data were recorded on a registration form, including demographic data, diagnosis, status of metastases, medical symptoms, medication, functional and psychological status, and social situation. The patients' development was observed at every visit and separately recorded by the doctors and nurses. Changes in functional status, symptoms, etc., and interventions executed by members of the palliative care team were recorded on the registration form during each visit, based on observation and questioning of the patient.

The registration form was first filled in by the coordinating physician (a general practitioner) at the first consultation to identify the need for palliative care. The registration form was a combination of clinical observations and questionnaires to be answered by the patient. Topics on the form included the patient's case history, diagnosis, metastasis, prevalence of symptoms, medication, intensity of pain and other symptoms (0–10 point scales), functional status (0–5 point scale), and psychological functioning.

Symptoms were recorded at the start of palliative care and throughout the care period. To

measure the intensity of pain, nausea, and breathing problems, numeric scales from 0 to 10 were used. A score of less than four was considered "low" and a score of greater than six "high." The changes in symptoms and pain were analyzed by comparing the number, type, and intensity of symptoms in the initial consultation and the last consultation before death.

The number of visits by the palliative care team members, as well as their actions, were noted on a separate form, with a list of (possible) interventions and open answers/comments. Once a month, the completed forms were sent to the research coordinator, who checked the data for completeness.

Patients were visited regularly, based on appointments made at the last visit or when it was requested by patient or family because of an emergency, complication, etc. Depending on the status and need of the patients, these visits ranged from daily to monthly. The frequency of appointments was also dependent on the location of the patient. In rural areas particularly, patients could not be visited as frequently as needed, due to transportation problems. Visit frequency also varied, especially during the last period of care, because of removal of the patient to another family member's home (daughter/son mostly), since more space was available to take care of the patients. This happened more frequently in urban areas. As a consequence of the removal that happened a few weeks before the patient died, the palliative care team could not continue its care.

Data analysis was carried out using the SPSS program, version 12.0. First, patients' characteristics (sociodemographic and medical) were presented, followed by a description of the type of interventions and the changes in symptoms and pain. A stepwise linear regression analysis was applied to look for factors related to changes in symptoms and the intensity of pain.

Results

The average age of the 102 patients, 52 women and 50 men, was 61.2 years. Most patients (75%) lived with their family, 15 patients lived alone, and 13 lived in other places (with friends).

Most patients were married. The income of most patients was low, that is, 97 patients had a monthly income less than 100 euros (Table 1). While most patients had social support from relatives, 11% of the patients had no social or financial support whatsoever. Half of the patients were taken care of by parents and/or children. Over one-third of the patients were taken care of by various family members, including children.

The most common primary diagnoses were lung cancer (18%), colon and rectum cancer (15%) and breast, cervical/uterus, liver, and stomach cancer (each 11%) (Table 2). The average disease duration until death was 19.5 months; for 33 patients, the diagnosis was known less than six months before death.

Metastasis was recorded in 71 patients (70%), and multiple metastases were noted in 34 of these patients. The most common sites of metastases were peritoneal (11%) and liver (10%). Comorbidity was reported by 98 patients. Comorbidity included diseases such as high blood pressure, diabetes, heart failure, and infectious diseases.

Table 1
Sociodemographic Characteristics of the Patients[a]

	n (%)
Age	
<35 y	3 (39)
35–50 y	15 (15)
51–65 y	32 (31)
>65 y	52 (51)
Gender	
Female	50 (49)
Male	52 (51)
Marital status	
Married	70 (69)
Widow(er)	21 (21)
Divorced	4 (4)
Single	6 (6)
Other	1 (1)
Monthly income	
<25 euros	13 (13)
25–50 euros	54 (53)
50–75 euros	23(22)
75–100 euros	7 (7)
>100 euros	5 (5)
Place of residence	
Rural	36 (35)
Urban	66 (65)
Social support	
Various family members including children	37 (36)
Children and/or parents	50 (49)
Brothers and nephews	4 (4)
No one	11 (11)

[a]Absolute numbers and percentages.

Table 2
Medical Characteristics of the Enrolled Patients[a]

Characteristic	*n*
Diagnosis	
Lung cancer	18
Colon/rectum/sigmoid cancer	15
Breast cancer	11
Cervical/uterus cancer	11
Liver/pancreas cancer	11
Gastric cancer	11
Head/neck cancer	6
Brain cancer	4
Leukemia	2
Melanoma	3
Ovary cancer	2
Urinary cancer	1
Other sites in the body	3
Unknown primary tumor	4
Disease duration	
<6 mo	33
6 mo–1 y	33
1–2 y	14
>2 y	22
Metastasis	
Multiple metastases	34
Single metastasis	37
None or unknown metastasis	31
Number of symptoms first consultation	
<5 symptoms	3
5–10 symptoms	24
11–15 symptoms	43
>15 symptoms	32
Intensity of pain[b]	
Low intensity of pain	20
Moderate intensity	34
High intensity	42

[a]Absolute numbers.
[b]Six patients did not report pain at enrollment.

The average number of symptoms at the first consultation was 13.4 per patient. Twenty-six different types of symptoms related to the illness were recorded during the first consultation. Loss of weight (96%), pain (94%), and fatigue (90%) were the more frequent symptoms mentioned by the patients, followed by loss of appetite (86%) and mouth problems (75%). Pain was the main symptom. The majority of patients with pain (51%) declared that pain had started in the previous year, whereas 17% had had pain for more than one year. At the first consultation, 44% of the patients mentioned a high intensity of pain (score of six or greater on a scale between 0 and 10) (Table 2).

A high level of nausea problems and breathing problems were reported by 11 and 10 patients, respectively.

Most patients (91%) received symptomatic medications; approximately one-quarter also received antineoplastic medications that were prescribed by their oncologists. Nonsteroidal anti-inflammatory drugs (23%) and opioids (50%) were frequently prescribed. The medications used by the patient at enrollment were prescribed by oncologists in most cases (73%); only 5% of patients had drugs prescribed by a family doctor.

The functional status of 80 patients was very low, that is, they were bed- or wheelchair-bound for over half the day. The majority of the patients (54%) reported serious psychological problems of anxiety and/or depression.

During the last evaluation prior to death, the average number of symptoms was 5.4 per patient, a decrease of eight symptoms on average. Nine new problems were recorded at the last consultation that were specific to the terminal stage of disease: anemia, coma, cathexia, delirium, bleeding, thirst, fever, paresthesia, and muscle cramps. The majority of symptoms decreased significantly after the start of palliative care (Table 3). Six patients reported an increase of symptoms between first and last consultation; these patients had cancer with multiple metastases, multiple medical complications, and relatives who had relatively poor compliance with the program.

For 30 patients, the number of symptoms decreased by five to nine symptoms; for 42 patients, the number decreased by 10 symptoms or more. Of course, the extent of the decrease is partly related to the number of symptoms at enrollment.

Both the frequency and intensity of pain declined. Pain was reported by 66 patients at the last consultation before dying and by 96 patients at enrollment. Thus, 30 patients with pain at enrollment reported being pain-free at the last consultation. Seven patients reported a high intensity of pain at the last consultation, as opposed to 42 at enrollment (Table 4).

Reports of fatigue (from 90 to 37), loss of appetite (from 88 to 53), and nausea (from 65 to 28) also reduced significantly between the first and last consultation. Breathing problems were mentioned by 38 patients at the last consultation, which was the third most common symptom mentioned by the patients at this stage, compared to the 10th most common (60 patients) at the first consultation.

Table 3
Changes in Symptoms Between Enrollment and Last Consultation[a]

		Number of Symptoms at Enrollment				
		<5 Symptoms	5–10 Symptoms	11–15 Symptoms	>15 Symptoms	Total
Number of symptoms at last consultation	<5 symptoms	2	10	23	20	55
	5–10 symptoms	1	14	17	8	40
	11–15 symptoms	0	0	2	3	5
	>15 symptoms	0	0	1	1	2
	Total	3	24	43	32	102

[a]Absolute numbers.

As mentioned, the average duration of the disease was 19.5 months. Most patients (89%) received palliative care for more than one month, while 8% received palliative care during the week before they died. The average period of palliative care was 61 days. The last consultation before death was conducted in the last 24 hours with 56 patients (55%). The final report on symptoms, therefore, was at a point close to death, and was made by a physician or nurse. For 26 patients (25%), this last consultation was made between one week and one month before death, and for six patients, it was more than one month before they died (Table 5). In these last cases, patients were removed to another area, so the team could not take care of the patient any longer. The teams provided care for an average of 10.2 weeks per patient (7.28 days of care in total).

The palliative care teams regularly advised changes in the medication regimen. This medication was prescribed by the oncologist or by the general practitioner of the patient, or the patient (and family) took medicines without prescription. After the first consultation, the patients received all the medication prescribed by the doctors of the teams. Two-thirds (67%) of the patients got treatment for symptoms; 72% of these patients received adjuvant medications; and 43% were treated with opioid medication. Almost one-quarter (24%) of the patients continued to use the same medications they were given at enrollment in the palliative care program.

During the period of palliative care, the patients also received various interventions by doctors and nurses (Table 5). Most frequently, counseling was mentioned as an activity (86 times by doctors and 72 by nurses). Interventions directed at relief and the evolution of the disease were made 75 times by the team doctors and 62 times by nurses of the teams. For doctors, these interventions included infiltrations, small surgical interventions, rectal touché, venous punctures, paracentesis, and thoracocentesis. The team doctor also frequently made recommendations for investigations to be carried out elsewhere.

Nurses' interventions directed at symptom relief included help with oral medications, enemas, artificial alimentation, use of deodorizers, oxygen therapy, etc. Nurses also frequently administered injections (88 times) and perfusions (59 times), and carried out functional exercises with patients (55 times).

Altogether, 10% of the patients received fewer than five types of interventions, whereas the majority, 84 (82%) patients, received

Table 4
Changes in Intensity of Pain Between Enrollment and Last Consultation[a]

		Intensity of Pain at Enrollment				
		No Pain	Low Pain	Moderate Pain	High Pain	Total
Intensity of pain at the last consultation	No pain	6	9	12	9	36
	Low pain	0	9	11	20	40
	Moderate pain	0	2	11	6	19
	High pain	0	0	0	7	7
	Total	6	20	34	42	102

[a]Absolute numbers.

Table 5
Palliative Care to 102 Patients[a]

Period of Care	No. of Patients
<48 h	5
48 h–1 wk	8
1 wk–1 mo	25
1–3 mo	40
>3 mo	24
Time between first and last consultation	
<48 h	8
48 h–1 wk	9
1 wk–1 mo	27
1–3 mo	40
>3 mo	18
Time between last consultation and death	
<48 h	56
48 h–1 wk	14
1 wk–1 mo	26
1–3 mo	5
>3 mo	1
Change in medication by the teams	
Yes	78
No	24
Interventions by the physician	
Counseling	86
Recommendation for investigation	45
Interventions by the team doctor directed at relief and evolution of the disease	83
Intervention by the nurse	
Counseling	72
Perfusions	59
Exercises for decubitus, breath, blood circulations	55
Interventions by nurse directed at relief and support	67
Number of visits by the physician	
<5 visits	42
5–15 visits	52
>15 visits	8
Number of visits by the nurse	
<5 visits	45
5–15 visits	47
>15 visits	10

[a]Absolute numbers.

between five and 10 types of interventions. Four patients received more than 10 interventions, and the same number of patients did not receive any intervention. Three of the latter four patients were enrolled in the program during their last 48 hours, and the other was in a pre-coma state.

During the period with the palliative care team, the patients were asked whether or not the medication and the doctors' and nurses' interventions had resulted in a decrease in the number of symptoms and a reduction in their intensity. Over half of the patients (56) stated that the team's interventions had had positive results for all their problems, and 34 patients said that the number of problems had decreased, so they experienced fewer problems. Five patients said that the medication and the interventions did not always have positive results.

After describing the main changes experienced and reported by patients, and after providing an overview of the palliative care activities of the teams, we analyzed which sociodemographic, interventional, and medical factors were related to changes in symptoms and changes in the intensity of pain. In a stepwise linear regression analysis, changes in symptoms, that is, a high decrease in the number of symptoms during the palliative care period, were significantly related to a high number of symptoms at enrollment, living in an urban area, and having low income (Table 6). The amount of variance explained by these four factors was 62%.

As might be expected, patients with a high number of symptoms at enrollment showed more improvement than patients with fewer symptoms. This is the most powerful predictor of the reduction of symptoms during the palliative care process, indicating the patients' needs at enrollment. Patients living in urban areas and on a low income reported a greater reduction in symptoms than patients living in rural areas on a high income. In the stepwise analysis, after step three, the total number of interventions ($P = 0.070$) and the number of interventions for relief and evolution of the disease by the team doctor ($P = 0.078$) showed only borderline significance, with a reduction in the number of symptoms between enrollment and the last consultation.

A decrease in the intensity of pain during the palliative care period was most strongly related to the intensity of pain at enrollment. Additionally, the interventions for relief and evolution of the disease by the team doctor,

Table 6
Stepwise Linear Regression Analysis, Change in Symptoms as Dependent Variable (96 patients)

	Standardized Beta	*t*	Significance
Number of symptoms at enrollment	0.649	8,753	0.000
Urban/rural living	−0.244	−3,251	0.002
Income	−0.134	−1,998	0.049

the change in the number of symptoms, and the social support and interventions for relief and evolution of the disease by the nurse all contributed significantly (Table 7). The explained variance was 42%.

Patients with a high intensity of pain at enrollment, and who received interventions for relief from the team doctor, reported a decrease in pain intensity and also showed a decrease in other symptoms, experienced strong social support from their family, and received less frequent interventions for relief from the team nurses. After step five in the regression analysis, the number of interventions was "borderline" significant ($P = 0.078$), with a high decrease in the intensity of pain, that is, many interventions were related to a strong decrease in the intensity of pain.

Discussion

This study shows the positive effects of at-home palliative care programs for cancer patients in Romania. The number of symptoms and the intensity of pain were used as main outcome measures. The quality of life of terminal patients is expected to be directly related to the number of symptoms and the possibility of controlling symptoms.[8] In the last months of their lives, these patients experience many problems that cause pain, immobilization, and anxiety, as was indeed the case with patients enrolled in the service.[7] At the beginning of the palliative care service, the teams assessed the health status of the patients, and the intensity of their symptoms, and they proposed interventions to manage the assessed problems.

Table 7
Stepwise Linear Regression Analysis, Change in Intensity of Pain as Dependent Variable (96 Patients)

	Standardized Beta	*t*	Significance
Intensity of pain at enrollment	0.446	4,998	0.000
Interventions for relief and evolution by team doctor	−0.374	−4,389	0.000
Change in the number of symptoms	0.292	3,181	0.002
Social support	−0.226	−2,626	0.010
Interventions for relief and evolution by the nurse	0.183	2,181	0.033

This study suggests that terminally ill cancer patients in Romania had a higher number of symptoms at enrollment in a palliative care service at home, with an average of 13.4 per patient, compared to another study where only 6.6 symptoms per patient were recorded.[7] This figure is an indication of the severe need of these patients without proper palliative care. The positive decreases in symptoms and in the intensity of pain are, of course, dependent on the number of symptoms and the intensity at the enrollment. Those patients with a high prevalence of symptoms and intensity of pain are more likely to improve. Indeed, this is what was found, but—as stated above—it also indicates a great need among these patients.

In contrast with some other studies,[9,10] we did not find an increase of specific symptoms or decline in functional status during the last weeks of life. The multivariate analysis did not show an effect of duration of treatment or disease duration on changes in symptoms and functional status. One explanation may be that the status of the patients was really worse—as we showed—so improvement is the major effect. Also, we believe, that the change in medication by the physician, counseling by both nurse and physician, and execution of exercises (to treat/prevent breathing problems, decubitus ulcers, etc.) had a continuous effect on improving and stabilizing the status of the patient.

The average number of symptoms at the last consultation was 5.4 per patient. This comes close to figures quoted in the international literature.

For Romanian patients, the most important symptom mentioned in both evaluations was pain, followed by fatigue, loss of appetite, and mouth problems in the first assessment on enrollment in palliative care. In the last assessment before death, the third most common symptom was difficulty breathing and a feeling of suffocation. Some authors have mentioned that asthenia (fatigue), loss of appetite, and dry mouth are the most distressing symptoms during the first assessment, whereas others have indicated dyspnea as the most important symptom.[7,15] However, other authors did not find that pain was the main symptom requiring the most

attention from the palliative care team, and/or pain did not have a high prevalence.[7,16–18] Pain is definitely a very important symptom for cancer patients in Romania. In this context, it is interesting to note that a recent study tried to assess the priority of symptoms for patients, which could be an effective approach in symptom management.[19]

In Romania, the use of opioid drugs for pain has been very complicated for a long time, due to both the attitude of patients and their families, and even of doctors, toward morphine, and the difficulty of prescribing this treatment due to bureaucracy.[2,7] For pain control, only 15% of patients were using a standard treatment recommended by the World Health Organization, whereas the other patients were using different proportions of nonopioid analgesics or other medication.[19,20]

The palliative treatment at home had a positive on effect on the number of symptoms and the intensity of pain and of other symptoms. These positive results are in accordance with findings from other international studies.[9,21,22] Indeed, this study makes evident that the delivery of palliative care by a multidisciplinary team at home improves the situation for the patients. The visits and various activities carried out by the team have a positive effect on the quality of life of terminally ill cancer patients.

The palliative care teams were very active and frequently visited the patients, providing the various interventions and activities for relief and support. It is interesting to note that medical conditions, such as the absence of metastases or comorbidities, and good functional status, were not related to a better outcome at the end of the palliative care process, nor was a better outcome related to the number of visits by the palliative care team. It seems that social and psychological factors had a direct effect on the number of visits by the teams, but that these visits are only indirectly related to the outcomes of palliative care.

The effect of the at-home palliative care interventions was more positive in urban areas compared to rural areas, when a decrease in the number of symptoms and a decrease in the intensity of pain are used as outcome variables. This finding might be explained by the lack of infrastructure and personnel in rural areas. Also, patients are often less informed about the progress of the disease and its terminal phase. Sometimes, family members prefer fewer medical interventions and less medical support.

The reduction of symptoms that was higher in an urban area was also more frequently reported among poor patients. The explanation may be that the new at-home palliative care teams have been more sensitive in looking out for these patients, who are also socially deprived.

It is not directly evident why strong social support from the family is related to a strong reduction in the intensity of pain. Maybe such family support coincides with better compliance with and acceptance of the teams' interventions. In the latter case, the findings show that, indeed, the number of interventions is related to a decrease in pain intensity. More specifically, it was especially the interventions for relief and disease evolution by the team doctor that contributed to a strong decrease in pain intensity. Apparently, a task division existed within the teams, because the nurses' intervention for relief did not contribute to this decrease. This was left to the doctor within the team.

Palliative care at home is a new service in Romania. It was developed in a standardized way in this project and was carried out accordingly.[15–24] It may be concluded that palliative care at home, as performed by the five teams, for terminal cancer patients was very effective in Romania. We strongly recommend further development of such palliative care services at home. They are not only effective; they also meet a great need experienced by cancer patients in Romania. Terminally ill cancer patients in Romania—as well in other countries—prefer to die at home, and palliative services at home result in patients having less pain and other symptoms.

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